



A Survey of Guardians of Persons Relocated from Northern Wisconsin Center (NWC)

For:

The Wisconsin Department of Health and Family Services (DHFS),
Division of Disability and Elder Services (DDES)

Prepared by:

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Executive Summary

Under a contract with the Department of Health and Family Services (DHFS) Division of Disability and Elder Services (DDES) with support from the Wisconsin Council on Developmental Disabilities (WCDD), APS Healthcare has conducted a mail and telephone survey of guardians of persons who have been relocated from the Northern Wisconsin Center (NWC). Background work on the survey was conducted in the late fall of 2005 between DDES and WCDD. APS Healthcare was brought into the survey process in early November to consult on the survey design, administer the survey and present the survey findings.

The survey was conducted between January 5, 2006 and March 12, 2006 via U.S. mail and telephone interviewing. The original mailing list consisted of guardians for 140 wards¹. However, three wards and two guardians were deceased at the time of the mailing, and two additional wards were removed from the final mailing based on feedback from their guardians, leaving a final list of guardians representing 133 relocated persons. Of the 133 remaining guardians, 101 completed the survey for a response rate of 76%.

Overall, reaction to the relocation effort at NWC has been positive among the guardians of the relocated residents. Findings from the NWC Relocation Survey suggest that NWC staff, county staffs and community provider staffs have worked well together at placing as many residents as possible into the community. With assistance from the guardians, these staffs appear to have done a very good job of matching residents with residential settings that offer them the greatest chance of success in their reintegration into the community.

Common feedback among the respondents falls into two broad categories, reactions to the relocation process and satisfaction with the community living arrangements. This feedback includes:

Relocation Process

1. Information regarding the relocation was generally available when requested and in a timely manner.
2. Guardians were adequately included in the relocation decision making process, but were not overburdened by their level of involvement.

Community Living Arrangements

1. Wards generally feel safe in their new settings and have increased opportunities for social interactions and participation in the community.
2. Most guardians indicate that their wards' social, emotional, health care and mental health care needs are adequately met in their new setting; however, several guardians did not feel that they could accurately make those judgments on behalf of their wards.

¹ Several guardians were listed for multiple wards, particularly if they were an agency/provider contact where the agency/provider was responsible for the ward.

3. Most guardians believe that their wards' overall happiness/satisfaction with their new living arrangement is either better or the same as it was while at NWC.

Respondents also noted some issues associated with the relocations process and their wards' community living experiences. These included:

Relocation Process

1. Poor communication between NWC, county, and community provider staff, and/or with the guardian and ward.
2. Complicated paperwork that was difficult to understand and complete.
3. Animosity between some NWC staff and community provider staff that may have impacted the quality of care of the residents as they transitioned into the community.

Community Living Arrangements

1. Some lack of opportunities for meaningful activities in the community and limited opportunities to interact with other people in the community.
2. Not all guardians felt that they had enough feedback on their wards to be able to judge their opportunities for meaningful activities and opportunities to interact with people in the community.
3. Approximately half of all respondents didn't feel that they had enough information about their ward to determine if they feel welcomed and valued in their community and 6% of the respondents indicated that their wards do not feel welcomed and valued by their community.
4. Fourteen percent of respondents were unsure if their ward receives appropriate mental/behavioral health care.

Based on the feedback from the guardians, both in their responses to the survey questions and in their additional comments, the positive experiences with relocation far outnumbered the issues discussed above. Overall, the relocation initiative appears to have been very successful for those residents capable of living in the community.

Introduction

Under a contract with the Department of Health and Family Services (DHFS) Division of Disability and Elder Services (DDES) with support from the Wisconsin Council on Developmental Disabilities (WCDD), APS Healthcare has conducted a mail and telephone survey of guardians of persons who have been relocated from the Northern Wisconsin Center (NWC). Background work on the survey was conducted in the late fall of 2005 between DDES and WCDD. APS Healthcare was brought into the survey process in early November to consult on the survey design, administer the survey and present the survey findings.

The NWC Relocation Survey was created to assess the experiences of former NWC residents who transitioned back into the community. The survey provides stakeholders and DHFS with information regarding the quality of life of the persons who have been relocated, and provides an opportunity to learn about guardians' experiences and satisfaction or concerns with the relocation process. The information collected by the NWC Relocation Survey can be used to improve future relocation processes and improve how the State communicates with guardians of individuals living in institutions about community living alternatives.

The survey was conducted between January 5, 2006 and March 12, 2006 via U.S. mail and telephone interviewing. Complete results of the survey are presented in this report.

Administration

The NWC Relocation Survey was originally drafted by DDES staff. The survey was then revised by APS Healthcare staff and shared with DDES for final refinement and approval. The final survey consisted of 28 questions and an area for additional comments not captured by the survey.

The survey was constructed using Teleforms™ software that allows the completed surveys to be scanned electronically into a database for analysis. Teleforms™ reduces the chances of data entry error and provides for rapid downloading of data to the repository database. Surveys were printed using Teleforms™ and then mailed to the guardian of record for each person relocated from the NWC. The guardians were given approximately two weeks to return the survey, at which time a second mailing was distributed to those who had not yet responded to the initial mailing. Approximately three weeks following the second mailing, APS staff began calling the remaining non-respondents requesting that they complete the survey. Each non-respondent was contacted a minimum of one time over a one week period. Several guardians completed the survey over the telephone, while others were left messages and completed the survey at a later date. There were also several no-contacts and some refusals. The disposition of each survey was logged and can be found in the table below.

Table 1: Northern Wisconsin Center Relocation Survey Dispositions January 5 th -March 12 th , 2006	
Disposition	Count
Returns	101 (including 2 deceased wards)
Non-Respondents	
No Answer/No Return Call	21
No Contact Information/Wrong Number	8
Deceased Ward	3 (not including the 2 returns)
Deceased Guardian	2
Incorrect Guardian Listed	2
Refusal	3
Total	140

The original mailing list consisted of guardians for 140 wards². However, three wards and two guardians were deceased at the time of the mailing, and two additional wards were removed from the final mailing based on feedback from their guardians, leaving a final list of guardians representing 133 relocated persons. One guardian indicated that their ward spent a short time at NWC but had not lived there for 25 years, while the other guardian stated that their ward had never lived at NWC. Of the 133 remaining guardians, 101 completed the survey for a response rate of 76%.

² Several guardians were listed for multiple wards, particularly if they were an agency/provider contact where the agency/provider was responsible for the ward.

Findings

The final survey contains two distinct sets of questions. First, respondents were asked to rate various items pertaining to how their wards' moves from NWC had gone. Second, respondents were asked to reflect on how they feel about where their wards are currently living. Respondents were also provided an opportunity to comment on experiences not captured by the previous two sections. The complete survey is included in this report as Appendix I.

How did your ward's move from NWC go?

Overall, the guardians were generally pleased with the relocation process of their wards. Responses to the survey questions imply that the relocation process was adequate for most guardians and wards; however, there is room for improvement. The open-ended responses provide several suggestions as to how the process could be improved, including reducing paperwork, expediting the relocation process, providing greater choice of living arrangement/locations, increased funding to support more community integration and providing pictures to consumers that illustrate the residential and service choices they have available.

Although the respondents suggest areas for improvement, their survey responses indicate that the relocation process met their needs in most cases. Ninety percent or more of the guardians indicated that someone was available to answer their questions, including staff from the county and the community service provider.

Typically, the best source of information regarding the relocation was county staff. Of the 87 guardians who provided feedback regarding their best source of information, 48%³ stated that county staff were their best source of relocation information, followed by NWC staff (29%), community service provider staff (21%) and other guardians/advocates (6%). Nine respondents (10%) stated that someone not captured by the above categories provided the best information about the relocation process. Some of these individuals included agencies, lawyers and specific case workers. When asked if the relocation information was provided in a timely manner, 95% of the guardians who responded said yes.

Guardians were asked if they participated in the decision about where their ward would live. Over 80% of the respondents indicated that they did participate in the decision about where their ward would live. The relocation survey also addressed the issue of overburdening the guardians with too many decisions regarding where their ward would live and how their ward would live. In both cases, almost 90% of the respondents indicated that they were not asked to make too many decisions regarding their wards. However, only 64% of respondents indicated that they made decisions regarding the services that their ward would receive, leaving 12% who indicated that they did not participate in these decisions and 24% who participated "somewhat" in these decisions. Overall, 94% of the guardians felt adequately involved in the planning process of

³ Several respondents selected multiple types of staff as their "best" source of relocation information. These responses are reflected in the percentages for each group, therefore the percentages do not total 100%.

relocating their wards. Detailed results from this section of the survey can be found in Table 2 below.

Table 2: Northern Wisconsin Center Relocation Survey						
How did your ward's move from NWC go?						
Questions 1-3				N	Yes	No
1. Was someone at NWC usually available to answer your questions about moving to the community?				99	90%	10%
2. Was someone from the county usually available to answer your questions about moving to the community?				97	92%	8%
3. Was someone from the community service provider usually available to answer your questions about moving to the community?				96	92%	8%
Question 4	N	NWC Staff	County Staff	Community Service Provider Staff	Other Guardians or Advocates	Other
4. Who was your best source of information about moving to the community?	87	29%	48%	21%	6%	10%
Question 5	N		Yes		No	
5. Did you usually get the information you wanted?	96		94%		6%	
Question 6	N	Yes		No	NA	
6. If you received the information you wanted, was it provided in a timely manner?	94	95%		1%	4%	
Questions 7-11	N	Yes		No	Somewhat	
7. Did you participate in the decision about where your ward would live?	98	81%		3%	16%	
8. Were you expected to make too many decisions about <u>where</u> your ward would live?	99	2%		90%	8%	
9. Were you expected to make too many decisions about <u>how</u> your ward would live?	98	2%		89%	9%	
10. Did you participate in making decisions about what services your ward would get?	98	64%		12%	24%	
11. Were you expected to make too many decisions about what services your ward would get?	95	2%		91%	7%	
Question 12	N		Yes		No	
12. Overall, were you adequately involved in the planning process to move your ward into the community?	96		94%		6%	

As mentioned earlier, the relocation process did not go perfectly for all guardians. Several guardians provided suggestions for improvement. Two of the more common concerns were a lack of communication regarding the move, particularly the options available to resident, and a sense that several of the residents were doing well at NWC and had no need or desire to move.

Along similar lines, most guardians felt that the care provided by NWC was very good. Several guardians commented that their wards were safe and well cared for. Common

concerns regarding the care provided at NWC included improving mental and physical activities available to residents and minimizing isolation. Of note, many respondents indicated that they no longer had these concerns now that their wards had been relocated to the community. For example, several respondents noted that the behavior of their wards is much more stable, allowing them to participate more fully in family events and community outings than during their time at NWC. However, there were cases reported where the opposite occurred and behaviors escalated once the ward was placed in the community. One guardian stated, “Now (his behavior) is unpredictable and I am not confident in his behavior so that I can be with him and our family without LSS staff along too.” Of the guardians who provided feedback on the relocation process and concerns with community placement, the majority view the change positively, particularly regarding their wards’ participation in the community and improved behaviors.

How do you feel about where your ward lives now?

To further examine the guardians’ feelings regarding their wards’ relocations, the Relocation Survey asks a series of very specific questions focusing on safety, services, health care and input into their wards’ care. For example, 95% of responding guardians indicated that their ward is now living in a safe place.

Guardians were also asked if their wards were receiving services that meet their social, emotional and mental/behavioral health needs. Over 91% of the guardians stated that their wards are receiving services that meet their social and emotional needs. However, there appears to be less consistency with mental/behavioral health care services. Less than 78% of guardians indicated that their ward receives services that meet their mental/behavioral health needs. Interestingly, 14% of guardians were unsure if their ward receives appropriate mental/behavioral health services. This finding appears to follow a general pattern in mental and behavioral health care for individuals with disabilities statewide. Mental and behavioral health services for these individuals are often disjointed due to different funding streams, and coordinating benefits can be complex because responsibility for providing these services can cut across several programs and/or agencies at the county and state levels. Receiving basic health care services received more positive feedback from guardians, with 92% stating that their wards receive adequate health care tailored to their needs.

Most guardians also feel that they have been kept adequately informed about how their ward is doing, as well kept involved in making decisions regarding services and supports for their wards. In both cases, 96% of the respondents felt well informed about their wards’ activities and adequately involved in their wards’ services and supports planning.

The remaining survey questions ask about the wards’ direct experiences with their new living arrangement, services and supports beginning with whether or not each ward receives appropriate services and supports. Eighty-six percent of the respondents indicated that their wards do receive adequate services and supports; however, 13% reported not knowing if their wards receive adequate services and supports. This finding suggests that guardians could be kept better informed about their wards’ service planning,

either by the county or provider staff. It may be useful to examine the procedures for sharing information with guardians for areas that could be improved or formalized.

Most guardians (87%) indicated that their wards have adequate opportunities for meaningful activities during the day, while some (10%) reported not knowing if their ward had adequate opportunities for meaningful activities. On a related question, only 78% of the guardians indicated that their wards have opportunities to interact with people in the community. Thirteen percent of guardians were unsure if their wards have opportunities to interact with people in the community, while 10% stated that their wards do not have these opportunities. In addition, only 51% of the guardians indicated that their ward feels welcomed and valued by the community. However, only 6% stated that their wards are not valued in their community. The remaining guardians were not sure.

Guardians were also asked to comment on their wards' overall happiness/satisfaction with their new living arrangements. The majority of the guardians (62%) indicated that their wards are happier/more satisfied now than before their move from NWC, while 32% stated that their wards' happiness/satisfaction is about the same as it was at NWC, leaving very few wards who were less happy after their move to the community. These findings suggest that despite the many challenges of community integration, most wards do better in the community than in an institutional setting.

Lastly, guardians were asked if their wards' needs would be met if the guardian was no longer able to serve as guardian. Over 72% of the guardians indicated that their wards' needs would be met, while 25% were unsure. This may be an area where state and county staff could assist guardians with planning for this possibility. Complete results from this section of the survey can be found in Table 3 below.

Table 3: Northern Wisconsin Center Relocation Survey
How do you feel about where your ward lives now?

Questions 16-18		N	Yes	No	Don't Know
16. My ward is living in a safe place.		94	95%	2%	3%
17. My ward receives services that meet his/her social needs.		95	94%	4%	2%
18. My ward receives services that meet his/her emotional needs.		93	91%	1%	8%
Question 19	N	Yes	No	Don't Know	No Applicable
19. My ward receives services that meet his/her mental health/behavioral needs.	94	78%	4%	14%	4%
Question 20		N	Yes	No	Don't Know
20. My ward receives adequate health care tailored to his/her needs.		95	92%	2%	6%
Questions 21-22		N	Yes		No
21. I have been kept adequately informed about how my ward is doing?		93	96%		4%
22. I am adequately involved in making decisions about the services and supports my ward receives.		93	96%		4%
Questions 23-27		N	Yes	No	Don't Know
23. My ward receives appropriate services and supports.		93	86%	1%	13%
24. My ward has adequate opportunities to have meaningful things to do during the day.		92	87%	3%	10%

25. My ward has opportunities to interact with people in his/her community.	95	78%	10%	13% ⁴
26. My ward feels welcomed and valued by his/her community.	94	51%	6%	43%
27. My ward's needs will be met even if I am no longer around, or able to serve as guardian.	96	73%	2%	25%
Question 28	N	Better than before he/she moved	About the same as before he/she moved	Worse than before he/she moved
28. My ward's overall happiness/satisfaction with his/her current situation is:	94	62%	32%	6%

Additional Comments

Respondents were given an opportunity to comment on issues not addressed by the Relocation Survey, or to comment on the survey itself (please see Appendix II for a complete list of comments). Forty guardians provided additional feedback, with most suggesting that their wards are doing well in the community, even in cases where the guardian was apprehensive about the move. The level of personal attention, as well as an increase in social interaction seem to be the two most common positive changes in the wards' lives following relocation from NWC.

This is not to say that there were not problems identified by the guardians. There appears to have been some animosity between the NWC staff and the staff of some community providers that became apparent to some of the guardians. In only a few cases did the guardians feel that this animosity affected the treatment of their wards. In most cases, both NWC staff and community provider staff were praised for the care they provided. Additionally, there was some concern over the complexity of the paperwork involved in moving the wards out of NWC. One guardian relied on her daughter to complete the paperwork, as she was unable to complete it on her own.

There were few comments regarding the survey. The two most relevant comments asked if the guardians would be receiving a copy of the Relocation Survey results and why the survey was being conducted in early 2006 when NWC was supposed to have closed in December of 2004.

Conclusions

Overall, reaction to the relocation effort at NWC has been positive among the guardians of the relocated residents. Findings from the Relocation Survey suggest that NWC staff, county staffs and community provider staffs have worked together well to place as many residents as possible into the community. With assistance from the guardians, these staffs appear to have done a very good job of matching residents with residential settings that offer them the greatest chance of success in their reintegration into the community.

Common feedback among the respondents falls into two broad categories, reactions to the relocation process and satisfaction with the community living arrangements. This feedback includes:

⁴ This row does not sum to 100% due to rounding.

Relocation Process

1. Information regarding the relocation was generally available when requested and in a timely manner.
2. Guardians were adequately included in the relocation decision making process, but were not overburdened by their level of involvement.

Community Living Arrangements

1. Wards generally feel safe in their new settings and have increased opportunities for social interactions and participation in the community.
2. Most guardians indicate that their wards' social, emotional, health care and mental health care needs are adequately met in their new setting; however, several guardians did not feel that they could accurately make those judgments on behalf of their wards.
3. Most guardians believe that their wards' overall happiness/satisfaction with their new living arrangement is either better or the same as it was while at NWC.

Respondents also noted some issues associated with the relocations process and their wards' community living experiences. These included:

Relocation Process

1. Poor communication between NWC, county, and community provider staff, and/or with the guardian and ward.
2. Complicated paperwork that was difficult to understand and complete.
3. Animosity between some NWC staff and community provider staff that may have impacted the quality of care of the residents as they transitioned into the community.

Community Living Arrangements

1. Some lack of opportunities for meaningful activities in the community and limited opportunities to interact with other people in the community.
2. Not all guardians felt that they had enough feedback on their wards to be able to judge their opportunities for meaningful activities and opportunities to interact with people in the community.
3. Approximately half of all respondents didn't feel that they had enough information about their ward to determine if they feel welcomed and valued in their community and 6% of the respondents indicated that their wards do not feel welcomed and valued by their community.
4. Fourteen percent of respondents were unsure if their ward receives appropriate mental/behavioral health care.

Based on the feedback from the guardians, both in their responses to the survey questions and in their additional comments, the positive experiences with relocation far outnumbered the issues discussed above. Overall, the relocation initiative appears to have been very successful for those residents capable of living in the community.

Appendix I – Northern Wisconsin Center (NWC) Relocation Survey

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Survey of Guardians of Persons Relocated from Northern Wisconsin Center (NWC)

Instructions: This survey is being conducted to learn about changes in the quality of life of persons who have transitioned into the community from Northern Wisconsin Center, and to learn about guardians' experiences and satisfaction or concerns with the relocation process.

Completing the survey will help us improve future relocations of other center residents. Your responses will not affect the services or supports your ward receives. Your responses will be kept confidential and the information you provide will not be individually reported. This survey is being sent to guardians of all persons who were relocated from NWC in 2003, 2004, and 2005. If you have questions about the survey, or if you would rather complete the survey by telephone, please contact Mary Green at 608-267-7803.

Please answer the following questions about the relocation of

who moved from NWC in _____ of _____ You may use the

space at the end of the survey to provide any additional comments.

How did your ward's move from NWC go?

Shade Circles Like This--> ●

Not Like This--> ⊗ ⊙

1. Was someone at NWC usually available to answer your questions about moving to the community?
☐ Yes ☐ No
2. Was someone from the county usually available to answer your questions about moving to the community?
☐ Yes ☐ No
3. Was someone from the community service provider usually available to answer your questions about moving to the community?
☐ Yes ☐ No

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4. Who was your best source of information about moving to the community?

- ☐ NWC staff ☐ County staff
☐ Community service provider staff ☐ Other guardians or advocates
☐ Other
(Please specify) _____

5. Did you usually get the information you wanted?

- ☐ Yes ☐ No (Who was unable to answer your questions?)

6. If you received the information you wanted, was it provided in a timely manner? (If you did not receive the information you wanted, please select "Not Applicable.")

- ☐ Yes ☐ No ☐ Not Applicable (NA)

7. Did you participate in the decision about where your ward would live?

- ☐ Yes ☐ No ☐ Somewhat

8. Were you expected to make too many decisions about where your ward would live?

- ☐ Yes ☐ No ☐ Somewhat

9. Were you expected to make too many decisions about how your ward would live?

- ☐ Yes ☐ No ☐ Somewhat

10. Did you participate in making decisions about what services your ward would get?

- ☐ Yes ☐ No ☐ Somewhat

Continue on Page 3

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11. Were you expected to make too many decisions about what services your ward would get?

☐ Yes ☐ No ☐ Somewhat

12. Overall, were you adequately involved in the planning process to move your ward into the community?

☐ Yes ☐ No

13. How could the relocation process be improved? **Please print.**

14. What was your main concern for your ward while he/she lived at NWC. **Please print.**

15. Do you still have this concern?

☐ Yes ☐ No ☐ Somewhat

If No, why are you no longer concerned? **Please print.**

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How do you feel about where your ward lives now?

16. My ward is living in a safe place.

☐ Yes ☐ No ☐ Don't know

17. My ward receives services that meet his/her social needs.

☐ Yes ☐ No ☐ Don't know

18. My ward receives services that meet his/her emotional needs.

☐ Yes ☐ No ☐ Don't know

19. My ward receives services that meet his/her mental health/behavioral needs.

☐ Yes ☐ No ☐ Don't know ☐ Not Applicable (NA)

20. My ward receives adequate health care tailored to his/her needs.

☐ Yes ☐ No ☐ Don't know

21. I have been kept adequately informed about how my ward is doing.

☐ Yes ☐ No

22. I am adequately involved in making decisions about the services and supports my ward receives.

☐ Yes ☐ No

23. My ward receives appropriate services and supports.

☐ Yes ☐ No ☐ Don't know

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24. My ward has adequate opportunities to have meaningful things to do during the day.

☐ Yes ☐ No ☐ Don't know

25. My ward has opportunities to interact with people in his/her community.

☐ Yes ☐ No ☐ Don't know

26. My ward feels welcomed and valued by his/her community.

☐ Yes ☐ No ☐ Don't know

27. My ward's needs will be met even if I am no longer around, or able to serve as guardian.

☐ Yes ☐ No ☐ Don't know

28. My ward's overall happiness/satisfaction with his/her current situation is: (Answer based on your knowledge of your ward's happiness.)

☐ Better than before he/she moved

☐ About the same as before he/she moved

☐ Worse than before he/she moved

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Additional Comments

*Thank you for completing this survey.
Please return the completed survey in the
enclosed postage-paid envelope.*

Appendix II – Guardian Comments

***Q4C: Who was your best source of information about moving to the community?
Other...***

1. Independent homes for better living.
2. all of the above
3. [REDACTED] case worker
4. [REDACTED] from [REDACTED]
5. We've had ten years experience doing this.
6. Lawyer for class action suit.
7. [REDACTED]
8. [REDACTED]
9. Me (I have the professional background).
10. Mostly [REDACTED]
11. Sorry - they were equal
12. A nurse
13. People at Center
14. Lawton & Cates, S.C.
15. The relocation process could be improved, by not having the client waiting half the day to be taken to the new location.

Q5A: Did you usually get the information you wanted? (If "No", who was unable to answer your question?)

1. It was a maybe/maybe not scenario
2. Sorry, don't really remember anymore!
3. This was a very unsettling time.
4. What there was to know?
5. County 51,437 services

6. I wanted to know if they had professional staff (nurse, aid, etc.) familiar with seizures and mentally challenged people.
7. To be taken care of properly and treated humanly

Q13: How could the relocation process be improved?

1. By not forcing the issue, i.e. by making it a mandatory matter that in itself severely limits available choices.
2. I really can't say as I found the new home for my daughter.
3. Yes. Seemed adequate.
4. Not really sure what this question means!
5. I think they did good job in the relocating process for my sister.
6. I would rather have him located nearer my home.
7. Very thoroughly done.
8. ■■■ should not have been relocated.
9. Went Fine - I was very satisfied. We tried long and hard with ■■■.
10. Funds available to pay for needed services for everyone to live in the community.
11. I think it was handled to my satisfaction.
12. NWC staff could have been more helpful. Many staff were so bitter about job loss that they did not share important information with ■■■.
13. By not having to move ■■■.
14. I was pro-active, but for those who did not or were not able to help their loved one, it may be that much more assistance would be required.
15. More communication from the final decision of moving him to a group home and until the person was moved.
16. With more notice (for all) perhaps.
17. It would have been easier on ■■■ if the whole process had been much quicker since she is so unsettled by any change to her routine.
18. I have no suggestions. I was always in the loop.

19. No improvement needed.
20. Thought it went well.
21. My social worker was [REDACTED], [REDACTED], she was excellent!
22. Thought the move went ok - just wasn't sure of all his things came with him. But all in all went ok.
23. Process was ok
24. The relocation went very well.
25. Provide pictures for choices. Provide names of guardians whose wards were relocated to suggested facilities.
26. The relocation went better than I expected.
27. We were fortunate to have a provider who worked at NWC and knew [REDACTED] so the transition went smoothly.
28. Less paper work! The paperwork was overwhelming at times.
29. I don't know. I was not directly involved, my sister was. She initiated the move long before our brother was to be moved and was an advocate for him.
30. The relocation went okay.
31. Needs no improvement
32. The relocation process was good.
33. I feel we had very few - or no options.
34. Relocation was stressful for [REDACTED] at first, but he has adjusted well.
35. It was a stressful environment for her, loud and rigid. Some aggressive people around her were demanding routine.
36. My county human services director should educate others - the process was very smooth here.
37. No comment.
38. Not knowing how when & where.

39. It went well
40. [REDACTED] has improved in behavior, speech, interaction with other people. She has an active life sociably and she has improved tremendously in all parts of her life since her move.
41. It went very well. Everyone was so helpful. Both NWC and NPI
42. I don't see anything that should be improved. [REDACTED] is very happy and content. The staff is excellent. They are also very good with him. I am very impressed.
43. (none) He's Happy where he is.
44. Nothing
45. The relocation went smoothly with the help of all [REDACTED] social workers.
46. It was timely.
47. They wasted time showing us places that did not meet [REDACTED] needs. People from the county-not always available-did not always answer voice mail-had to call many times.
48. The county staff needs more comprehensive training and help when it is forced to place persons with severe multiple disabilities and health problems in the community.
49. It was fine.
50. Much More Communication Too Vague
51. It was very orderly and well organized.
52. It couldn't be improved. He's getting good care where he's at. Very happy.
53. Looking into more of the conditions of the person and also the family more time to check out other resources.
54. Things were pretty much based on "the bottom dollar". No matter how many times I said [REDACTED] should not be moved, the move was a "dollar" decision for the state.

Q14: What was your main concern for your ward while he/she lived at NWC?

1. I had been overall more than satisfied with the services [REDACTED] had been receiving while he was living at NWC violent out bursts were one of primary concerns.

2. None
3. Her safety
4. One on one attention
5. To receive the best medical treatment possible to insure the best quality of life possible for [REDACTED]
6. He was not happy. He ran away a couple of times.
7. I am always concerned about his eye sight - he became blind in one eye while he was at NWC. Was never really told about how this happened before or after this occurred.
8. Had no concern, was satisfied
9. I think they did a good job taking care of my sister!
10. That he receive kind, loving care
11. [REDACTED] level of care at NWC was adequate. He had been a resident there for 45 years.
12. I was satisfied with his care there.
13. She had a good home, no complaints. I think it is a big mistake to move them out.
14. To be moved into the community as soon as possible - had been asking for 3 years and no action taken until people were told they had to move clients to community.
15. There were none.
16. Continuity of care with as little disruption as possible
17. That staff would care about her and treat her well.
18. Her quality of life, medication and overall personal care.
19. My concern often was that my brother did not get to be outside and was very pale. He also had marked acne.
20. None - I was very pleased with him at the Northern Center. My main concern was the moving to apartment to apartment and building to building.

21. [REDACTED] was happy and well cared for at NWC. We were pleased with the care she got was well supervised.
22. The number of times she became violent and had to be restrained - concerned for her safety, as well as the safety of those around her.
23. I and my parents were always happy with the care [REDACTED] received at NWC
24. Quality of care and services.
25. That he had enough space by himself.
26. Adequate care, supervision, food and lodging.
27. That she was safe and taken care of.
28. I had no concerns.
29. That his needs were met - and had things to do to occupy his time.
30. Too far to travel from [REDACTED]
31. It was too far for us to visit and stay overnight. We can visit every week or two now.
32. None - [REDACTED] got excellent care.
33. Was appreciative turnover of staff was minimal because of ward's limited communicative staff
34. That she would be located in a place where she would be abused or neglected.
35. Health care.
36. [REDACTED] has pica and that will always be a concern although both NCW and his new home use the utmost care to prevent him from ingesting foreign objects.
37. That he will be comfortable and safe.
38. Being able to manage [REDACTED] medical behavior needs.
39. That she would be forced to move from NWC.
40. I had no concerns. He was extremely cared for.

- 41. Level of care: physical and emotional needs being met as well as special health needs.
- 42. That he was in a safe place.
- 43. Distance
- 44. That he was taken care of properly and he seems to be doing well.
- 45. None - he had a nice home at [REDACTED].
- 46. No main concern, he was well taken care of.
- 47. No concerns. I felt he was safe and well cared for.
- 48. That he would have the least restrictive environment in a safe, (for him), caring setting.
- 49. None
- 50. Take good care of him, keep him active.
- 51. She is in a warm, relaxed home that provides individual care and privacy if she chooses. She receives good care and I am very satisfied with her placement.
- 52. That she would be safe, happy and not agitated by others.
- 53. Get good care.
- 54. It was good for many years, but at the end they weren't being very nice to her. They even locked her out of the building one day and when the [REDACTED] staff arrived, she was outside without a coat.
- 55. Safety
- 56. No comment
- 57. If she was getting good care and was but she wasn't happy and didn't feel safe I don't think.
- 58. None
- 59. [REDACTED] was too confined in her ward. NWC performed a miracle in her behavior and other needs, since coming in from Winnebago institute.
- 60. Being active and doing activities; both mentally and physically.

- 61. Safety & it's a one on one home. He is happy. (not an institution)
- 62. There wasn't any
- 63. We could not visit her often enough because of the distance we had to travel.
- 64. Too many wards.
- 65. I had no real major concerns about NWC [REDACTED] & I was very satisfied and happy about the quality of care [REDACTED] received.
- 66. Feeding Problem
- 67. She was well-taken care of there at NWC. The people were very good to her while she was there. She was there many years.
- 68. To maintain a safe, secure, stable, stimulating environment.
- 69. She would get away and run.
- 70. That he got the best & most quality of life possible, whatever that be. Think he was with too much low level wards
- 71. There were no concerns. He was given medical attention when needed, able to work at [REDACTED] skill level. He was treated with respect and given choices for food and able to sit in his leather rocker.
- 72. They treated him very well-I had no concern
- 73. He couldn't have been in a better place. The staff and care was great.
- 74. security she likes to run
- 75. No matter where my ward lived, my biggest concerns are him getting the proper health care, and being protected from another ward or staff.
- 76. She was so far away. She didn't get good care the last 2 years.
- 77. Stability-too many moves within NWC.
- 78. He had good care.

Q15: Do you still have this concern?

1. This concern has increased with [REDACTED] being in the community. I believe he is in a much more precarious situation now than he had been at NWC. But this had been a concern that I was told didn't matter since [REDACTED] had to return to community whether he or I liked it or not.
2. He ([REDACTED]) was enjoyable for me (his sister [REDACTED]) to be with on outings. Now is unpredictable and I am not confident in his behavior so that I can be with him and our family without [REDACTED] staff along too. Makes visits very awkward to have stranger he brings with. Also they do not try to include family in thier parties. Also very repetitive in his communication. Used to be better at discussing something
3. No. Because there are only females caring for my daughter and there are only 5 clients total in the home I chose.
4. No. Only two residences at this location.
5. It seems she is being adequately cared for
6. [REDACTED] is now very happy.
7. Seems to be doing OK.
8. Because she is being taking care of very good!
9. Distance. [REDACTED] new home is very convenient for me to see her. [REDACTED] has been out more in the last year than her lifetime.
10. [REDACTED] has been moved from a group home to the [REDACTED] County Health Care center.
11. I never was concerned because they kept me well informed.
12. The living arrangements for [REDACTED] have been perfect - we couldn't have asked for a better arrangement.
13. [REDACTED] is doing so well! He is happy, relaxed, has a great complexion and goes on many outings in the community. He is much loved by the staff and so comfortable. I am very thankful!!
14. He has moved.
15. [REDACTED] is well supervised at her home now.
16. Since she has been moved she seldom has violent episodes and restraints haven't been necessary - only redirection to a padded "safe" room.

17. He is much calmer without so many people around.
18. She no longer lives there.
19. They seem to keep [REDACTED] busy with the daily household chores and have plenty of outings planned each week for him.
20. Site was moved to WI where I'll be able to visit her at least once per year.
21. We see [REDACTED] so much more now.
22. I have met new care givers. They brought [REDACTED] to my home. [REDACTED] behavior is good, and I believe this is an indicator.
23. She moved.
24. Ward has 1 on 1 care. 24 hrs staff is closely supervised on a daily basis.
25. [REDACTED] seems happier where he is now.
26. Ward lives in same city that I do.
27. N/A
28. I keep in touch with [REDACTED] and continue to offer suggestions regarding daily life, i.e. chores, social proprieties etc. that should be reinforced by staff.
29. The [REDACTED] staff has a way of handling her with love. They have never restrained her. They have a "safe room" where she can go if she is upset.
30. I am no longer concerned because I was always satisfied with her care N.W.C.
31. She's very happy and she calls the group home her home now. Isn't flustered and feels like a home to her so she isn't destructive anymore.
32. n/a
33. [REDACTED] has attended weddings, showers, baptisms, parade, fairs, and many other activities. She participates in household chores, goes shopping, and works outside the group home.
34. I know she is doing much better in a group home environment. There is more 1 on 1. She is doing so many more things and going places in the neighborhood, being a smaller group.

35. Because in a private home now.
36. [REDACTED] is now located in [REDACTED].
37. She has own room and less wards.
38. [REDACTED] has been back to the community for 6 mos. already. She was supposed to receive some kind of daycare or stimulation during the day. Van transportation to the Health Care etc. Nothing has been done yet. [REDACTED] is in the house all day with not outside activity. Except when she has been sick and had to go to the clinic to be seen by the Dr. Also I had stopped one day while she was sick to check on her. She was having a seizure, eyes moving up & down, fists clenched and jerking. All the care giver said was "that's the most active [REDACTED] has been all week. I did not answer. Just surprised she did not recognize a seizure, knowing [REDACTED] has them.
39. Feeding Tube was inserted.
40. Because she does not even try to get away.
41. He was removed from that environment and placed in a home in the community. The workers do not have a background dealing with seizures-only with mentally disabled individuals.
42. [REDACTED] is now in private home near [REDACTED].
43. They always call and let us know what's going on. Beautiful home.
44. These doors are alarmed, & less people for providers to watch at one time
45. The year he has been at [REDACTED] his health is properly tended to and there is always someone around him, but there is still fear from a staff member or ward on my mind, has he is totally defenseless
46. [REDACTED] died 9/29/2005
47. [REDACTED] is out in the community
48. [REDACTED] is deceased.

Additional Comments:

1. I appreciate the opportunity to complete this survey. My general dis-satisfaction with the whole transfer situation was that [REDACTED] over-all safety needs were being addressed more than adequately while he was at WWC. However, those same safety needs are much more inadequate with he is relocation in the community that this issue was not at all addressed by the State, I feel, did not at all do him and his high medical needs any justice. In fact, [REDACTED] is now at a much higher risk. [REDACTED]
2. What caused [REDACTED] & his family to know he needs their staff with us is temper tantrums he had had when going to family outings using verbal and physical outbursts as a regular occurrence. I never had these problems before with my brother so it's a mystery to me why its happening now!!!
3. My daughter's physical and mental condition is improved. Mental because she gets more attention which she loves and there is more mental stimulation at the home where she resides. Many times I have wished I knew about her present home a long time ago! It is ideal and I pray she can remain there.
4. We were always satisfied with care she had over 40 years at NWC. The move to [REDACTED] has been great for [REDACTED]. She seems to be happier and has less daily problems. She is lucky to have a great and caring staff taking care of her. Everyone was great during and before the move. We were kept well informed on a timely basis and were able to visit soon after the move.
5. Since I live several states away ([REDACTED]) I have only been able to visit my ward on one occasion in July 2005 - those of us who visited her (my wife, sister, niece and cousins) felt she was in a favorable environment + she seemed to be doing quite well - we look forward to the continued best care that [REDACTED] can offer her
6. By my observations, [REDACTED] and her staff, are very loving people, I am very happy with [REDACTED] living arrangements. He is very happy.
7. My son [REDACTED] had a rough start at the group home because they were not really prepared for him. He did a lot of destruction to the home the first month he was there. Fortunately, they got to know [REDACTED], and he adjusted to them. Every thing is much better now, and he is doing better and looking really good, and seems more content! The staff at the group home seems really good to [REDACTED] and he seems to really like them. The 5 other people who reside there are more relaxed and they don't bother [REDACTED] and he doesn't bother them. This was not the case at NWC. There were peers there would hit or bite him! I would get calls there occasionally about this!
8. She is doing very, very good! She like's her new home! And I get to see her now.

9. As indicated [REDACTED] was placed in a group home Nov 2004. The facilities were fine. However, I do not think [REDACTED] ever adjusted to his new home. [REDACTED] experienced numerous lengthy seizures resulting in a number of ambulance trips to the hospital. Last spring or early summer [REDACTED] started losing weight which resulted in tests. One evening following some testing [REDACTED] became sick and heaved which resulted in aspiration pneumonia and lengthy stay in the hospital. At that time [REDACTED] refused to eat. [REDACTED] was then transferred to the [REDACTED] County Health Care Center with comfort measures ordered. After one day or so in the [REDACTED] [REDACTED] resumed eating and has gained back all his weight. I believe that [REDACTED] thought he was back in the NWC (home) again. A move that nearly resulted in [REDACTED] death was unnecessary. [REDACTED] brother/ guardian.
10. I hated to see [REDACTED] leave NWC, as I was happy with his care there. But, I'm very happy with his new home. They are doing a good job of caring for him and he seems very happy there.
11. After living in a hospital setting as [REDACTED] was I felt he maybe would not survive going elsewhere. He seemed to adjust faster than I expected. I am most pleased. He is very well liked by the staff and all others that come in contact with him. This is not saying that he does not have bad moments but they are at his home know how to get him back to his own mild self. [REDACTED].
12. My brother's home was built to meet his needs and the needs of his 3 friends who live in the home. Great strides have been made to secure the best medical help available. The staff is competent, caring and very loving atmosphere exists at the home.
13. [REDACTED] is so happy since she is under [REDACTED] care, no doubt due to the one-on-one attention she now receives compared to living in a ward at NWC where the attention had to be shared by many. We have been extremely delighted with [REDACTED] and the individuals who work with [REDACTED]. It has been upsetting to watch as NWC employees verbally attacked the [REDACTED] organization and made nasty remarks about [REDACTED] and her roommate to the local [REDACTED] newspapers. We've appreciated all the NWC has done for [REDACTED] in the past, but when "the dust settled", it appears that [REDACTED] is now living in a real "home" environment with people that really love her and enjoy caring for her, for the first time in her life since she was a young teenager. We are extremely happy with her living situation now!
14. A young man at [REDACTED] [REDACTED] house is tearing the new house apart. He pulls off chair rails, TV's to the floor and anything attached to the walls, down. To my knowledge, he has not attacked any of the residents. [REDACTED] has very strong hands and fingers. If [REDACTED] starts to attack residents, I hope the state will look into taking [REDACTED] back to a state facility. [REDACTED]
15. We live in [REDACTED] and cannot visit as often as we would like. It's difficult, therefore, to answer yes or no. This is the reason for "don't know".

16. I was very happy with NWC and I was concerned about client adjustment to new situation. Client is doing excellent. NWC also had excellent staff.
17. I'm optimistic concerning her relocation to [REDACTED].
18. I was really not involved with relocation as I had asked several years ago to be relieved of my guardianship duties. I continued to receive information and consented to the move. I am, at present, not familiar with any of his activities
19. [REDACTED] receives adequate care and services but not as good compared to care and services she received at NWC. Will you be sending the summary results to guardians? I would like to see them.
20. I, as guardian was apprehensive about relocation because my daughter's communicative skills were very limited and subtle. Immediately after relocation she flinched when staff approached and cared for her. After some period of time staff became acquainted with her and she with them. My only source of reference is how residence with one of [REDACTED] houses. The staff there is outstanding! They care for her in a loving efficient manner and are open and communicative with me. My contact with liaison with county and her new residence is very satisfactory too.
21. Our situation worked out beautifully: much better than I imagined it could. Her care givers are wonderful!
22. [REDACTED] has had some real challenges with health behavior health. Improvement has been seen but, more needs to be done.
23. We have a great social worker ([REDACTED]). But, we have been dismayed at some of the protocol involved with certain re-certification processes. The people involved were distant, difficult to deal with and border lined on rudeness. Sometimes flexibility and even a small fragment of warmth goes a long way.
24. I am my brother's standing guardian. Therefore, I don't make primary decisions concerning him. I do feel adequately informed by staff as to his well being, especially if they can't reach my sister, his primary guardian, they do call me.
25. I was worried about change for my son, but, he has adjusted just fine.
26. Some of the questions I feel I'm unable to answer, because my son is nonverbal. From my own observation he seems to be doing o.k. However, I'm concerned about his safety at certain times. I'm still of the opinion that a more sheltered environment would be better for someone like my son. I do not see where people in the outside community accept retarded people.

27. Guardian mentor programs were most helpful. I think some older parents/guardians were too fearful of the process. It involved a tenacious and very worrisome year to find the right provider. A year later, and the oversight on my part continues. I'm lucky, I have a younger sibling in the area who was appointed "stand by guardian" so the oversight could continue in the event that I could not continue.
28. Northern Center was not much help when it came to [REDACTED] replacement. They were not kind to the people of [REDACTED]. I don't understand because [REDACTED] had to be moved so I guess they were upset about losing their jobs, but that was not an excuse as far as we are concerned!
29. [REDACTED] is receiving the same adequate care that she was getting at NWC, just at a different location!
30. The place we got for her was the best thing we could have done. [REDACTED] care givers - NWC, aides and nurses played a big part in choosing this place for her. They were caring people.
31. I fought against [REDACTED] being moved from NWC as I was very happy with the way she was treated and the way they treated us. When she had to be moved I interviewed every agency that said they would take her. I also made to a list of things I expected them to do. I finally made the choice to go with [REDACTED]. I am very happy with them. They have done everything I expected them to do and more. NWC was also very helpful in moving [REDACTED] and getting her adjusted. She seems very happy in her new home.
32. My wife [REDACTED] past away July 2-05 [REDACTED].
33. [REDACTED] always got very good care at NWC. She is now in [REDACTED] at [REDACTED] homes and gets good care and services. Thank You
34. We can go see her more often.
35. I think he is much happier when he is allowed to sit in his rocker. We were visiting when there was a shift change. Neither let him sit in his chair. Hey did give him candy for a treat. He could use exercise or massages to help his muscles keep working. I am called when he doesn't want to take his meds or he has behavioral problems. He listens better when given choices or when someone explains what and why they are doing something. When the worker gave him a choice of milk or juice, he responded better to their other suggestions. He cannot talk but does know some sign language. He understands simple commands. He was much happier at the Northern Wisconsin Center. They treated him like family.

36. [REDACTED] County Social Services has done an outstanding job in helping to place [REDACTED] in an outstanding home. His care taker must have come right out of heaven. [REDACTED] invites me to 2-3 staff meetings each year. She is great.
37. [REDACTED] is total care and he got wonderful care at NWC. The staff and everyone were really great. It was sad such a wonderful place had to be closed. He is getting good care now too. The workers there are all really great too. It's wonderful they have great places I like these.
38. Upon her move she didn't get her own bed. She bought it from her own money. It's some-where in storage. I would like them to find it and give it to her. As its hers & it matches her dresser. Sincerely [REDACTED] P.S. I didn't receive this until Feb. 6,2006
39. Q24-[REDACTED] I don't feel was able to interact due to her disability. Q28- It is hard for anyone to answer, how do I know. Hopefully people were good to her. I think parents should be told about the amount of paper work that is involved after they leave the colony. Thank God one of our daughters did it. We were happy to have [REDACTED] close to home the last year. [REDACTED] will always be our angel and I know she is getting lots of love and touches from the angels. [REDACTED]
40. Why the survey now? NWC was to be closed by December 2004.